

Population Health Matters

Population Health Forums

Moving The Needle: Challenges and Opportunities in Communicating Patient-Centered Outcomes Research

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March 20, 2013

The Patient-Centered Outcomes Research Institute (PCORI) is an independent non-profit research organization charged with the task of helping the public make informed decisions and improving health care delivery and outcomes by producing high-quality evidence-based research. PCORI was authorized by Congress as part of the 2010 Patient Protection and Affordable Care Act (ACA). Bill Silberg, Director of Communications at PCORI, shared an insightful overview of PCORI's mission and initiatives at a recent Forum.

Silberg first described PCORI's commitment to seeking input from a diverse range of stakeholders, including patients. Patients and caregivers are viewed as a meaningful part of the research team and Silberg discussed the importance of bringing a broad range of voices to the work of PCORI. Silberg used the term "research done differently" to characterize the way in which PCORI strives to shape its purpose.

Silberg went on to discuss the details of the National Priorities for Research and

the Research Agenda which include: assessment of prevention, diagnosis, and treatment options; improving health care systems; communication and dissemination research; addressing disparities; and accelerating PCOR and methodological research. These priorities are intentionally designed to be broad and process oriented.

The PCORI Board of Governors has approved a number of pilot projects throughout the United States. The projects are predominantly population specific, and focus on ways of engaging patients in research and the dissemination process. Examples include a project on how physicians and patients talk to one another more openly, to a pilot project on the use of mobile apps for patient caregiver attitudes, behavior, and knowledge, and a project on reducing disparities in a rural population with multiple cardiovascular disease risk factors.

Throughout his presentation, Silberg acknowledged that comparative effectiveness research (CER) and PCOR

are not the easiest topics to communicate to the public, but he believes that PCORI can build visibility, focus on results and lessons learned, and discover powerful patient stories that can be shared.

As Silberg pointed out, "moving the needle" requires significant change in researcher culture, norms, attitudes, skill, and policies. There are multiple influences and constraints acting simultaneously on stakeholders and researchers. He stressed the importance of identifying key stakeholders and the need to plan collaborative activities as a way to effect change. Silberg explained that change will occur slowly and requires a long-term, multi-phase/multi-component plan. The focus should be on facilitating awareness, promoting education and training, facilitating feasibility, establishment of comprehensive range of incentives and rewards. Simply put, "research done differently." ■

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